



LINCOLN CHAFEE

U.S. SENATOR

RHODE ISLAND

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RHODE ISLAND RECEIVES \$150,000 FOR ASSISTANCE TO CHILDREN WITH BIRTH DEFECTS

WASHINGTON, DC – U.S. Senator Lincoln Chafee announced today that the Rhode Island Department of Health (RIDOH) has been awarded \$149,989 from the U.S. Department of Health and Human Services. The money will be used to identify children with birth defects and assure they receive the necessary services and referrals for appropriate care. Of the approximately 13,000 births annually in Rhode Island, 725 babies on average are diagnosed with a birth defect.

“Providing appropriate care for those born with birth defects is essential to lightening the burden of parents who are faced with this challenge. We must reach out to those parents and help inform them of the resources available,” Senator Chafee said. “This program will specifically assure that all children born with birth defects are provided with important avenues of treatment as well as for the education of parents and caregivers,” he continued.

The funding will directly benefit Rhode Island’s Birth Defects Surveillance Program (RIBDSP), which resides in the Division of Family Health at the RIDOH, and identifies newborns with birth defects using hospital discharge data. Its goals are to assure that children with birth defects are identified and health care services are provided in a high-quality and cost-effective manner. The data compiled by RIBDSP is linked to a population-based information system developed by Family Health called KIDSNET, which receives prompt information on all births. This information then becomes available online to pediatric care providers who are connected to KIDSNET. Children who are not receiving services are identified and provided outreach through Family Health’s Family Outreach Program (FOP).

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The RIBDSP plans to enhance its current system by broadening its case ascertainment methods and utilizing additional sources of data, including those from Women and Infants Hospital, Rhode Island Hospital, and child hospitalization data. These sources will improve the timeliness of case ascertainment. The RIBDSP also plans to work with the FOP and visiting nurse agencies to assure outreach and follow-up for children identified with problems.

Additionally, the RIBDSP will inform and educate parents and health care professionals about birth defects in an “integrated and culturally competent way.” The RIBDSP will achieve these goals through partnerships, information sharing and dissemination, and ongoing program evaluation.

Funding will pay for a Project Director, a full-time data manager, parent consultants, a part-time epidemiologist, as well as a part-time clerk. Staff from KIDSNET, Newborn Screening, Data and Evaluation and Health Statistics will also participate in the project.

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